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Critical Reflections on Self-Management Support in Chronic Disease: The Value of Occupational Therapy in Health Promotion

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Amid debate regarding the particulars of reform, the landscape of health care is changing. The increasing burden of chronic disease, combined with a recognition of soaring health care costs, demands a reexamination of established models of care. Traditional services are reactive and emphasize disease-focused and episode-specific remediation. These frameworks fragment care between providers and settings, thus limiting outcomes and inflating costs and use. A shift, therefore, to integrated proactive models of care that emphasize a continuum of intervention and prevention is advocated. Such a shift is important to promote individual, community, and population health while decreasing costs (Institute of Medicine [IOM], 2003; Leland, Fogelberg, Halle, & Mroz, 2016).

Self-management support is one instrument with the potential to promote health in the context of chronic disease. It is defined as "the systematic provision of education and supportive interventions to increase patients' skills and confidence in managing their health problems" (IOM, 2003, p. 52). Self-management extends from individuals' engagement in medical behaviors to coping with participation restrictions and the emotional sequalae of living with disease. Support extends beyond the provision of knowledge to collaborative techniques that facilitate problem-solving and the activation and navigation of the health care system (Lorig & Holman, 2003; Packer, 2013). Via self-management support, individuals' participation in their own care can decrease costs and use and increase overall health (IOM, 2003; Lorig & Holman, 2003; Udlis, 2011).

In the context of health care reform, initiatives, such as the National Prevention Strategy (U.S. Department of Health, 2011), highlight the significance of health promotion and self-management support. It has taken a health care crisis for legislation to acknowledge the need for health promotion. Furthermore, despite emerging legislative and regulatory backing, health care professionals report continued challenges and discomfort with implementation of self-management support (Mudge, Kayes, & McPherson, 2015; van Hooft, Dwarswaard, Bal, Strating, & van Staa, 2016).

Surface tensions between self-management support and traditional practice patterns (i.e., issues of time and reimbursement) can potentially be attributed to underlying macrocontextual perspectives of health and medicine. Macrocontextual perspectives, or Kuhnian paradigms, are pervasive views held by large groups of people, such as societies or cultures. They are taken-for-granted assumptions that are generally not questioned and usually not even acknowledged. While abstract in nature, they have pragmatic implications, as they shape individuals' beliefs and actions. Paradigmatic influences may explain the reluctance in Western society to embrace health promotion on the level of both the system and the clinician. Explicating these influences is important to understand barriers to meaningful change.

In occupational therapy, specifically, there is emphasis on the need to capitalize on the opportunities of the evolving heath care system by moving beyond disease-focused models of rehabilitation toward promoting health through occupation (Pizzi & Richards, 2017). The value of occupational therapy in health promotion has been attributed to the profession's emphasis on client-centered care, processes of performance patterns and skills, and outcomes of participation, which are all components of self-management support (Leland et al., 2016; Packer, 2013). A more fundamental explanation of the value of the profession for health promotion may be occupational therapy's optimal positioning to resist pervasive views of health and medicine.

Critical Reflections

What is Health?

The goal of health care is unequivocally health; however, a consensus of what health *is* is not as easily achieved. Western medicine is infused with structuralist and reductionistic philosophies that

shape the traditional conceptualization of health as the absence of organic or physical pathology. Influenced by a Cartesian dichotomy, health thus excludes psychosocial influences and ultimately the human experience (Wilcock & Hocking, 2015). Critics of reductionistic views of health have advocated for more holistic definitions, such as that of the World Health Organization (WHO, 2014): "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (p. 1). The WHO's seminal definition moves beyond the physical body to encompass psychosocial elements. In addition, it views health not merely as an absence of a negative trait, but rather as the presence of a positive attribute of well-being. While there is considerable debate as to the definition of well-being, it may potentially be viewed as a state of optimization encompassing the totality of the human experience, including physical, mental, and social aspects (Wilcock & Hocking, 2015). While the WHO's definition rejects reductionistic views, it retains the traditional emphasis on organic pathology. The absence of organic pathology is a necessary and sufficient element of reductionistic definitions of health, and it remains necessary (although no longer sufficient) for the WHO's definition of health. The retention of the necessary criterion of absence of organic pathology is problematic for individuals with chronic conditions and diseases characterized by long-standing and often nonremediable physiological impairments. In addition, while the WHO's definition encourages a more holistic view of health, it predicates health on absolute or complete states of well-being, a utopian view that may not be realistically attainable (Wilcock & Hocking, 2015). Conceptualizations of health that are bound to the absence of physical impairments and/or necessitate an ultimate state of physical well-being are incompatible with ongoing disease states. Thus, such definitions significantly limit the potential of individuals with chronic disease to experience health.

Self-management support facilitates individuals' abilities to experience health even while living with disease. Therefore, the outcome of health in the context of self-management support is incommensurable with traditional views. As an intervention, self-management support, which does not aim for a cure, is devalued when operating in the paradigms described in the previous paragraph. Even for clinicians who ostensibly use self-management support, reductionistic influences result in a disproportionate emphasis on strategies, such as medication adherence and exercise that targets body functions and structures (Packer, 2013). However, individuals report increased benefit from supportive interventions that also address the psychosocial sequalae of illness and the effects of disease on daily life (Dwarswaard, Bakker, van Staa, & Boeije, 2015). A focus on medical management in clinical practice is often simplistically attributed to reimbursement models that emphasize concrete and measurable outcomes. However, it is important to recognize that reimbursement models not only reinforce traditional paradigms but are also a product of those paradigms; thus, the problem of reimbursement is at its heart a problem of worldview.

While health in the context of self-management support does not align with traditional paradigms, it is compatible with an occupational perspective. An occupational perspective of health does not necessitate the absence of organic pathology and does not assume a utopian view. Consistent with a philosophical basis of pragmatism, it recognizes a capability-focused process of adaptation (Yerxa, 1992). It considers limitations in health in the context of Meyer's (1922) "*problems of living*" and "habit-deterioration" (p. 4). And it recognizes active involvement in occupation and the meaningful use of time which are elements of self-management, as a means of experiencing health (Meyer, 1922; Wilcock & Hocking, 2015). From an occupational perspective, health is not incompatible with the presence of disease and is a human experience that is possible, and indeed accessible, for all.

What is Medicine?

Intertwined with questions surrounding the domain of medicine or health are questions about the rightful practice of medicine or care. Western health care is historically strongly embedded in paternalistic models in which an expert takes care of an individual (Katz, 1984/2002). Infusing the traditional worldview are power relations that expect the individual to obey the expert's orders. There are also strong moral obligations intrinsic to the relationship with the expert holding responsibility for the individual's well-being and the individual having a duty to comply. With the heightened significance of self-determination and autonomy in contemporary bioethics, the concept of informed consent has been added to the medical relationship. However, while clinicians continue to provide treatment in a traditional paradigm, individuals' involvement in care is limited to agreeing to an expert's prescription versus a true collaborative approach as embodied by self-management support (Katz, 1984/2002).

To embrace self-management support fully, clinicians must relinquish their sole possession of the expert role. They must recognize that, while they possess expertise in the disease, the individual possesses expertise in the experience of the disease. However, clinicians have trouble relinquishing control, even with an ethos of caring, as maintaining control in the medical relationship is perceived as beneficial for the individual (Mudge et al., 2015). Because of the pervasiveness of paternalistic views, even clinicians who use self-management support may still be operating in traditional models of control. They may use what they perceive as support; however, if the goal of the intervention is merely to facilitate compliance with clinicians' recommendations, the self has been stripped from self-management and with it the full potential of the individual to experience health (Udlis, 2011). In fact, the pervasiveness of traditional paradigms is demonstrated through clinicians' reports that some individuals are incapable of engaging in self-management (Phillips, Short, Dugdale, Nugus, & Greenfield, 2014; van Hooft et al., 2016). Such a view fails to acknowledge that all individuals are self-managing, whether effectively or not (Lorig & Holman, 2003). Those who are living for extended periods with illness are inevitably engaging in their own medicine. Therefore, it is the individuals who clinicians perceive as incapable of self-management who may have the greatest need for self-management support (Phillips et al., 2014; van Hooft et al., 2016). However, recognition of the ubiquitous nature of self-management is limited by the process of professionalization in which medicine was moved from the community to the institution. That shift also restricts individual activation, as it encouraged ceding of control to an expert with the expectation of obtaining a cure (Lorig & Holman, 2003). Therefore, the problem of control is multifaceted, with clinicians finding it difficult to relinquish control and individuals finding it difficult to accept control. A paradigm of health care compatible with self-management support necessitates a return from the sole domain of the medical expert to the domain of the individual, from the clinic to the community and the home.

While issues of control influenced by perspectives of paternalism limit the self in self-management, barriers to the use of support also exist. Support is at odds with an individualistic culture, as its relational nature requires a high degree of collaboration and fluid boundaries of shared responsibility between parties. In an individualistic culture, therefore, self-management support is often limited to the clinician providing information and expecting the individual to be able to act independently on those facts (Mudge et al., 2015). While control may be partially ceded to the individual with such an approach, persistence of strict division of responsibility between the parties restricts support in its fullest sense. In fact, individuals with chronic disease engaged in self-

management report the inadequacy of information provision and the need for additional relational support (Dwarswaard et al., 2015). The integration of relational support is further challenged by its intangible nature, which conflicts with the Western emphasis on the concrete and observable. Clinicians and even members of society perceive increased value in hands-on versus hands-off interventions. However, to actualize the full potential of self-management support for health promotion, clinicians must transition from doing to talking and "from talking to listening" (Mudge et al., 2015, p. 8).

Occupational therapy foundational principles are compatible with self-management support that incorporates both self and support, which empowers individuals to embrace personal definitions of health. The profession is grounded in client-centered practice and recognizes the expertise of individuals in living their lives (Gupta & Taff, 2015). Rooted in humanistic perspectives, occupational therapy believes in the individual as "an agent who is the author of health-influencing activity" (Yerxa, 1992, p. 79). Appreciating the agency of the individual, Meyer (1922) states, "Our role consists in giving *opportunities* rather than prescriptions" (p. 7). The idea of opportunity inherently acknowledges the self or an individual's will, recognizing his or her freedom to accept or reject versus a moral obligation to follow passively. Furthermore, the relational nature of support can be appreciated through an occupational lens in which the construct of self-management support is viewed as a co-occupation: an occupation that intrinsically involves interactive engagement (Pierce, 2009). In its purest form, self-management support comprises an intricate and fluid "dance" between the parties where engagement by one agent is insufficient in the absence of engagement by the other agent (Pierce, 2009, p. 203). Thus, merely providing information without ensuring the individual can incorporate it into daily life is inadequate to meet the criteria of self-management support. Viewing self-management support as a co-occupation rejects an individualistic perspective of isolated and bounded responsibilities and shifts to a relational view where the actions of one agent are inherently and continuously influenced by the actions of the other.

What is Good?

Intertwined with questions about health and medicine are broader questions of what is good, a construct subject to ongoing debate by philosophers and ethicists. Although an extensive exposition is beyond the scope of this article, the good is inextricably intertwined with ethical considerations of self-management support. The traditional Hippocratic oath enjoins nonmaleficence and beneficence, causing no harm and doing good, which are compatible with paternalism (Katz, 1984/2002). Therefore, decreasing clinician control with self-management raises serious ethical concerns, since relinquishing accountability may result in harm to individuals. The argument against self-management, however, is predicated on the assumption that the good is defined by the clinician's beliefs and professional norms (Dwarswaard & van de Bovenkamp, 2015). In this framework, a benchmark of self-management is often a dichotomous view of compliance with a clinician's recommendations versus a more fluid continuum of adaptation experienced in daily life (Mudge et al., 2015; Udlis, 2011). Thus, while ostensibly supporting self-management, clinicians may force their own definitions of self-management, imposing on the individual a value-laden good. However, autonomy, another bioethical principle, does not support a conceptualization of good as defined by another since it is inconsistent with self-determination. Therefore, embracing self-management support in a traditional worldview raises ethical tensions between the principles of autonomy and beneficence (Dwarswaard & van de Bovenkamp, 2015; Mudge et al., 2015).

Moving outside of traditional paradigms, self-management support may be understood as balancing and even blending autonomy and beneficence (Oprea, Braunack-Mayer, Rogers, & Stocks, 2010). The collaborative model of self-management support embraces a shared definition of the good through the expertise lent by each party. It appreciates the role of established clinical recommendations but also recognizes the unique and expert lived knowledge of the individual in determining the good. Such a view is consistent with occupational therapy's humanistic and agentic roots expounded earlier, as Meyer (1922) urges respect of "the native *capacities and interests* of the patient" (p. 7). Self-management support "redefines patients' medical interests in terms of their broader life goals" (Oprea et al., 2010, p. 62). The good thereby shifts from an expert-determined disease-focused conceptualization to one consistent with Meyer's (1922) focus on "living" (p. 9). While self-management support does not impose the clinician's perception of good, neither does it abandon the individual to take control of his or her own care. Autonomy thus shifts from an individualistic view to a relational view of collaboration between clinician and individual (Katz, 1984/2002; Oprea et al., 2010). The clinician's responsibility is not lessened but instead is transformed from responsibility for the individual to responsibility to the individual (Dwarswaard & van de Bovenkamp, 2015). Thus, in the paradigm described in this paragraph, autonomy and beneficence are no longer at odds but rather complement each other to realize the good, or the individual's optimal experience of health as living.

Implications for the Profession

As elaborated in the previous section, traditional Western conceptualizations of health and medicine restrict the implementation of self-management support and its potential to promote health. In contrast, the compatibility of self-management support with foundational principles of occupational therapy may enable the profession to optimize health in individuals, communities, and populations. However, despite the alignment of self-management support with occupational therapy as a profession on a philosophical level, individual occupational therapists may face similar challenges in practice as clinicians from other professions.

The pervasiveness of macrocontextual perspectives of health and medicine affect both the power and status of health care professions as well as accepted practice models. Therefore, despite long-standing philosophical tensions with medicine, occupational therapists often align themselves with medical care to increase professional recognition and obtain necessary reimbursement (Gupta & Taff, 2015; Wilcock & Hocking, 2015; Yerxa, 1992). Working within medical models, occupational therapists' beliefs are implicitly shaped by traditional macrocontextual perspectives, which influence the prioritization of interventions in the constraints of limited time and resources.

Embracing the full potential of self-management support requires occupational therapists to resist macrocontextual perspectives of health and medicine. The first step to resistance is explicating the fundamental principles of a worldview, a process to which the current reflections contribute. The pervasiveness and normalization that characterize paradigmatic principles make visualization difficult. However, occupational therapists are optimally situated to see beyond the traditional paradigm since they have their profession's founding principles to draw on as an alternate worldview. Their preparation to transcend implicit biases that influence clinical practice patterns contributes to their ability to embrace self-management support in its fullest sense, thus augmenting the profession's value in health promotion.

To encourage resistance, individual clinicians should engage in critical self-reflection on their beliefs and clinical practices. In addition, educators should critically examine curricular components

and ensure that the professionalization of young members is consistent with the profession's founding principles. For example, prioritization of biomedical interventions over self-management support in professional training is itself a product of traditional paradigms. Such an emphasis both undermines the skilled nature of support and devaluates the intervention as noncurative. However, when viewing self-management support as a co-occupation, the importance of training in supportive interventions cannot be underemphasized. Much as individuals require knowledge, skills, and confidence to engage in their part of management, clinicians require knowledge, skills, and confidence to engage in their role of supporter (Mudge et al., 2015; van Hooft et al., 2016).

While the present analysis is not intended to be an exhaustive treatise on philosophical and ethical influences on self-management support, it is hoped that these emerging critical reflections will contribute to the ongoing discussion of the unique value of occupational therapy for health promotion. Although aligning with medicine may be viewed as necessary for the short-term survival of the occupational therapy profession, such a position threatens the long-term viability of the profession by obscuring its distinct contributions (Gupta & Taff, 2015). By resisting macrocontextual perspectives of health and medicine, occupational therapists can embrace the full potential of self-management support as a means of facilitating an occupational perspective of health. Such an approach will not only benefit the individuals, communities, and populations they serve but also reinforce the value of the profession.

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